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ABSTRACT

This report describes a program for handicapped infants which emphasizes early treatment as a prime means of preventing more serious physical and behavioral problems later in life. Also, the program focuses on the entire family of the developmentally disabled, including infant, parents, and siblings. Program objectives include (1) increased stimulation and environmental enrichment for the infants, (2) enhanced communication in the family, (3) training for interested university students, and (4) promotion of early case finding by various community members. Thirty-three developmentally disabled infants and their families were involved in the program in its first year. Assessment of effectiveness was attempted through parent interviews and testing of the children. Preliminary results suggested that there were positive benefits for those children who attended the program frequently. Discussion focuses on further research needs and questions. (DP)

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A FAMILY ORIENTED ENRICHMENT PROGRAM FOR HANDICAPPED INFANTS[1]

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6 tables
3 figures

A FAMILY ORIENTED ENRICHMENT PROGRAM FOR HANDICAPPED INFANTS* +

Setsu Furuno, Ph.D., MSPH and Kitty O'Reilly, RPT, MPH

The research literature has been extensive in discussing the merits of early stimulation with disadvantaged populations (1, 2, 3), with those of outstanding intellectual competence (4), and with premature infants (5, 6). Studies involving intervention with handicapped infants or those with significant developmental delay or mental retardation are of more recent origin (7, 8). Assisting parents in the stimulation of handicapped and retarded infants should be of considerable concern in view of the distress and the anxiety experienced by parents at the discovery of their child's abnormal condition.

Much of the literature about families with handicapped children suggests that a parent's perplexity and grief about a handicapped infant impedes his providing for the child the dimensions of stimulation that he might ordinarily provide for his normal child. As Lemkau states, "The problem for the person who wishes to preserve as much as possible the normal development of the personality of the handicapped child is to see that the deprivation and understimulation he suffers are minimal." (9).

This is a report of a program for handicapped infants which began in September, 1971. Its theme was simply that: Parents of normal children seek advice and help in rearing their children; parents of handicapped children should have equal access to the specially oriented guidance they need. Additionally, we cannot assume that the handicapped child's development proceeds in the same way as the normal child's, only more slowly. Many children with developmental

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delay have specific motor handicaps that need specialized treatment. Others must be patiently taught all those things normal children learn almost independently and, to this end, repetition and reinforcement techniques are necessary. Even such a simple matter as learning to focus attention must be taught to many of the infants. Crawling, imitative learning, and even self-protecting skills must be demonstrated. Most essentially for those of us in public health, we would emphasize one of its basic tenets, that early treatment is one of the prime means of preventing the development of secondary and tertiary handicapping conditions; both physical and behavioral.

Another important facet in our concern for the infant with developmental delay relates to the feelings and adjustment of siblings. In essence then, the concern is with the total family: parents, siblings, and the handicapped infant.

The goals of this project of early stimulation of handicapped children, birth to 3 years of age involving the total family were:

1. To provide an enrichment program for developmentally disabled children as early as possible to help them towards optimal functioning.

2. To enhance communication between parents, and to assist in relationships of siblings to the handicapped child and family.

3. To serve as a training center for university students from different schools and departments.

4. To promote early case-finding whereby members of the community, particularly physicians and hospital nurses, will be alerted to early diagnosis and referral.

This paper will describe the program and report on the year's finding of early intervention with families of handicapped infants.

Format of Program

The program was held at Leahi Hospital in Honolulu, Hawaii, at a center utilized during the week for intensive in-patient care for handicapped children.

The program was held from 9 to 12 noon every Saturday morning from September 1971 to June 1972. Evening meetings were arranged twice a month to provide a resource for those parents who were working on Saturday. The focus of the Saturday program was instruction and demonstration of stimulation activities by consultants who volunteered their time on a scheduled basis. The procedure was to have the instructor demonstrate a lesson, and staff members and other volunteer consultants assist the parents to work with the children on different skills. These included: (1) physical therapists teaching gross motor skills; (2) occupational therapists demonstrating feeding techniques and development of fine eye-hand coordination; (3) nurses and educators presenting the rationale and examples of teaching children body image using mirrors around the room; (4) staff members stressing the utilization of all the senses, e.g. taste, smell, touch, hearing, feeling and seeing; (5) psychologists presenting the theory and practical application of behavior modification; (6) speech therapists discussing and demonstrating language training.

Two hours of instruction and demonstration and interaction with and among families were followed by a "parents only" group session, while infants napped or were cared for by student helpers and Girl Scouts. Here the parents had an opportunity to query the instructor for the session and to discuss their problems and concerns with staff and other families.

Birthdays and other special events were celebrated at the Saturday sessions to provide for as much of a normalizing experience and family participation as possible.

The program also served as a fieldwork setting for students from various departments and schools at the University. These included: the Schools of Nursing, Social Work, Education and Public Health including maternal and child health and nutrition students; Department of Psychology, and the Division of Audiology and Speech Pathology of the School of Medicine. It also served as a

center for observation by community workers in child development or in handicapped children programs.

Assessment of program effectiveness was provided through parent interviews and testing of children.

METHOD

Subjects

Thirty-three developmentally disabled infants and their families participated in the program. The diagnostic categories of the children included the following: 16 Down's syndrome, 7 with psychomotor retardation, 5 with cerebral palsy and 5 with various other problems. (See Table 1). Ethnic backgrounds of the families included: 12 Japanese, 8 multiracial, 8 Caucasion, 2 part-Hawaiian, 2 Filipino, and 1 Chinese. Demographic data on subjects are presented in Table 2.

Insert Tables 1 and 2

Referrals were accepted from any source: physicians, the Health Department, voluntary agencies, public health nurses and parents. (See Table 3). When a referral was received, the coordinator made a home visit to explain the program, evaluate the child and invite the family to participate.

The ages of infants ranged from 2 months to 3 years. (See Table 4).

Insert Table 3 and 4

A. Parents

Parental attitudes related to their developmentally disabled child were assessed by interviews from a schedule adapted from Zelle, (10). These were conducted on 23 of the 33 families by staff members and students from the School of Public Health and Social Work. Eight families were not interviewed because they were no longer with the program and two could not be contacted.

Although interview questionnaire data are not always suitable for parametric testing, correlational analysis was performed on the parents' responses to provide

an indication of the interrelation between attitudes, demographic data and infant developmental progress. We are aware that such results must be interpreted cautiously, but as a first approximation and basis for discussion, results of this analysis will be reported.

The program is currently developing a data collection system that should provide for a more solid analysis.

Parents were grouped into high and low attenders to determine whether there were significant differences between the groups. Attendance of families at the program was obtained by the percentage of meetings they attended out of the total possible they could have attended. For the total group of 33 families the range of program attendance was from 0 to 92 percent with a mean of 39 percent and a median of 36 percent. A total of 36 sessions were held.

Of the 23 families interviewed, the 11 above the median were labelled high attenders and the rest were low attenders.

B. Infants

All of the handicapped infants were tested on admission to the program and re-tested approximately six months later. The tests used were the adapted Gesell Upper and Lower Extremity Motor Development Tests (11), and the Denver Developmental Screening Test (12). (The Bayley Infant Tests (13) were also administered to the children, but re-tests are scheduled on an annual basis, so none are yet available.)

Of the 33 children in the program only 19 were in long enough to have pre-test and post-test data available. In order to analyze the test results, the items on the Denver were scored to give an approximate developmental level in each sub-test.

A ratio was calculated for the 12 pre and post sub-tests by comparing the developmental age and chronological age. To determine the rate of change which occurred, differences in pre and post-tests were computed. The assumption for using primarily the rate of change score was that it could present a clearer picture of what might have happened in the six months the child was in the program

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as compared to the span of time prior to referral. Since the absolute values of developmental levels in this population may always be depressed, the rate of change value gives a means of analyzing progress using the child's past rate of development as his own control. The formula used was as follows:

$$\text{Rate of change} = \frac{D.A.^2 - D.A.^1}{C.A.^2 - C.A.^1}*$$

RESULTS AND DISCUSSION

A. Parents

Correlational analyses show that high attenders demonstrated a greater awareness and realistic understanding of their child's problem than did low attenders. These parents were most frequently the parents of Down's syndrome children, which may demonstrate that this is an easier problem for parents to handle, perhaps because of the very precise information that can be given about it, as opposed to the more generalized category of "psychomotor retardation."

High attenders put fewer restrictions on their activities outside the home because of the handicapped child; showed more overall progress in learning to meet the needs of their child, and demonstrated better problem solving abilities. The latter relate to recognition of problems, taking the initiative to seek solutions and utilization of community resources to assist them.

Other significant correlations associated with high program attenders were:

(1) They tended to be families of older infants; (2) there was positive interaction between all family members; (3) husbands belonged

*$D.A.^2$ = Developmental age at post test; $D.A.^1$ = Developmental age at pre test; $C.A.^2$ = Chronological age at post test; $C.A.^1$ = Chronological age at pre test.

to fewer organizations; (4) they were referred by public health nurses. This may indicate some consistent follow-up which kept the families motivated. A summary of these findings are presented in Table 5.

Insert Table 5

Other significant relationships are presented in Table 6. These results indicate that the amount of care needed by the child was most pronounced in the youngster diagnosed as cerebral palsied, and there was a corresponding increased change in the rountines of daily living, e.g. adjustments in eating and sleeping arrangements. Likewise, there was a high correlation between the necessity for a change in the total family activities and restriction of the parent's activities with the presence of a cerebral palsied child.

Insert Table 6

For Down's syndrome children, there was a significant positive correlation with the ability to fit more readily into a normal family life at this early stage.

Those families which found it necessary to change some of their educational-occupational goals after the birth of the handicapped child also had an increased restriction in the activities of the parents. It is also interesting to note that in these cases, the husbands tended to belong to more organizations.

Most parents had not considered the possibility of placing their child in an institution yet, but those who had also demonstrated an increased participation in outside activities perhaps in an effort to avoid the conflicts of decision-making and every day handling of the child.

The parents in the older age range indicated positive changes in each other as a result of having the handicapped child, and also an increase in ability to communicate with each other. Likewise with an increase in

communication in general, there was positive agreement between husband and wife regarding their goals for the future and on methods of child rearing in relation to the child. Generally as these positive aspects of an integrated family life tended to exist, there may have been a lessened need to use outside activities as an escape from the problems at home.

B. Infants

Pre-post scores for the sample of children (n=19) were compared using two tailed t tests. The rate of change for the group shows no significant pre-post differences except for the Personality Social section of the Denver which had a t=2.55 and was significant at the .05 level. Although high attenders exhibited an increase on all post tests except for lower motor functioning (Fig. 1), high intra-group variability contributed to a failure to identify significant pre-post differences from attendance effects.

Insert Figure 1

Looking at individual data, we note that 10 of the 19 infants demonstrated in the post-test for at least one sub-test a rate of improvement which was equal to or greater than the advance in their chronological age (i.e., a rate of 100% or more improvement.) This can be contrasted with the pre-test scores when only one child showed any advancement at or beyond the 100% level. All of the 19 children improved to some degree in rate on at least one sub-test; 14 showed no change in one sub-test; and 5 showed increases in all sub-tests. One child had a decrease in rate in one sub-test.

Figures 2 and 3 present samples of rate of change on two children, with diagnoses of cerebral palsy and Down's syndrome respectively, selected to demonstrate the types of differences among the children.

Insert Figures 2 and 3

In looking at the comparative rates of development of the individual children, we note that in most cases where there is a spurt of development in one sub-test, there may be a corresponding decrease in another sub-test. Correlational analysis bears this out where there was a significant negative correlation between developmental rates ($r = -.51$) of language and gross motor skills.

Ten of the nineteen youngsters had spurts of increase in the language skills; eight of the ten had a corresponding lack of improvement in gross motor or lower extremity skills. These appeared to be in two developmental age categories: seven were showing pre-language development in the 1-6 month range, where the items tested are responses to sound vocalization and laughing and three were in the 6-20 month range of development, which includes beginning verbalization and imitation of speech.

Five youngsters showed a decrease in language development corresponding to an increase in gross motor or lower extremity skills. The motor skills which appear to take precedence over language skills occurred at 3 different stages: at 1-5 months, were those learning to roll; at 6-12 months, were those learning to creep and cruise, and at 12-19 months, were those learning to walk.

Two youngsters showed a decrease in language development while showing an increase in personal-social skills.

Seven youngsters had simultaneous increases in language and personal-social skills were the developmental ages tended to be in the same range as the language development scores.

Figure 1 demonstrates this point where the rate of change in lower extremity motor development was lower on the post-test than on the pre-test while nearly all other areas showed an increased rate of change.

The literature reports similar findings. Gesell notes that during the period of rapid locomotor development (12-15 months), the adaptive and

language areas slow down. Smith (14) noted a drop in vocabulary gains at 12-18 months when the child is trying to learn to walk.

Bayley (15) found a difference between sensori-motor and adaptive items where the sensori-motor peaks at age 6 months and falls off almost entirely by 12 months. The adaptive skills show a gradual increase until 8 months, levels off until 12 months and then has a sharp increase to 18 months, continuing a more gradual climb thereafter.

The variations in development which these scores demonstrated had no relation to any of the factors which might be considered predictive, such as high vs. low attendance at the program or additional speech or physical therapy. Therefore, it is postulated that the variability may be similar to the growth curves of normal children, where one phase of development slows down in rate while the youngster concentrates on learning a new skill, in a different developmental area.

The alternative explanation might be that because a large proportion (66%) of these children have motor handicaps, e.g. the hypotonia of Down's syndrome and the neurological impairment in the cerebral palsied, gross motor, and lower extremity motor development may progress at a much slower rate than the areas of personal-social, fine motor, and language development.

Descriptive Data

Results related to other aspects of the program are essentially descriptive. To promote early case finding, the authors discussed the program using a slide presentation for pediatricians at Children's Hospital, Health Department staff from Honolulu as well as the neighbor islands. The program was also written up in the morning paper as a bylined article by its science writer who observed the program for a Saturday morning. The feature article was picked up by a United Press reported who circulated it through many local papers on the mainland. A television presentation was also made by the second author. The effect of some of this dissemination has

been a program which began with 10 families in September and expanded to the present number of 33. The referrals have continued to increase with 14 new referrals during the three summer months. New referrals are tending to include fewer Down's syndrome and more with the non-specific diagnoses of psychomotor retardation, or delayed development. In addition, more referrals are now coming from private physicians and public health nurses.

As children reach the ages of 2½ to 3 years, they have been placed in daily group programs in the community. Sixteen children were referred out during the year. Seven went to the Health Department Child Development Centers, 1 entered the United Cerebral Palsy pre-school, 3 are in the Hawaii Association for Retarded Children Centers, 2 were referred for short-term intensive training at an in-patient facility, 1 was sent to a day-care center for retarded children and 1 Down Syndrome child entered a normal pre-school.

Siblings

While we did not progress significantly in organizing a structured program for siblings, they participated in planning parties for themselves and their handicapped siblings, helped with preparation of materials, and served as models for demonstrations. We can only relate anecdotally some of the positive effects on siblings:

1. A child who never left her handicapped younger brother alone, became interested in the play activities of other siblings and was able to allow her brother to fend for himself.

2. A child who stuck close to her mother and was obviously anxious that her parents attend "school" for her younger handicapped brother, was eager to participate in demonstrations, and was later able to attend her own hula class with her father, leaving the center during the last hour on Saturdays.

3. Some of the siblings who were younger than the handicapped child participated actively with their parents in the exercises that were being

demonstrated.

We would also report from observation that parents not only were interested in working with their own child, but were seen to move about to help other children and to encourage and visibly rejoice in their progress.

Parents' Comments

Parents' comments also indicate that they appreciate knowing that they are not alone and learning specific ways of working with their child. They state that explanations about the child's handicaps done in an unhurried way, also help them become more realistic and accepting. Some parents have complained about the group becoming too large and thus limiting the individual instruction that they felt they needed.

Parents whose children had individual language sessions, indicated that they found them extremely helpful. Parents also endorsed strongly the work of the nutrition student who obtained diet records and counseled parents about their infants diets.

SUMMARY

The primary effort of this paper is to suggest the use of a family oriented model for working with handicapped infants early. Results which can only be regarded as preliminary, suggest that there were positive effects from such an early stimulation program for those who attended more frequently than those that did not. We are well aware, however, that results reflected were from interviews administered at the end of the year rather than a pre and post comparison. The results, at best, raised a number of questions for further study:

1. Based on results of parents of older infants demonstrating better coping behavior, do parents then need to have achieved a certain level of adjustment in order to respond more adequately to an informational-demonstration program?

2. What is the significance of an increased rate of change in personal-social tasks on the DDST?

3. What would be the effect of more frequent contact between professionals and families?

4. Why were there no significant differences among infants of high and low attenders?

We will have an opportunity to respond to some of these questions through the program instituted as of July of this year.

Both staff and parents saw the need after a 6 months' period for a program where the children can attend on weekdays to obtain more group work and more intensive, motor, sensory and language training, as well as the Saturday program. To this end a grant from the Bureau of Education of the Handicapped was applied for and received. Supplementary funds from the Social and Rehabilitation Service which allowed us to begin this program on such a modest basis have also been received.

Present programming involves attendance by children during the week for 1, 2, or 3 days depending on their developmental levels. Thirty children will be serviced with some children exclusively on a home program. Mothers who are not working will attend the program once during the week to learn about the programming for their child, while fathers and siblings will attend on Saturdays. Mothers who work will attend on Saturdays with their families in order to receive the lesson for their child during the week.

In order for the Center to serve as a model, planning will be directed towards a design which will be replicable with regard to methods of delivery of the program, curriculum development, staffing patterns, parent training and equipment needs.

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TABLE 1 Diagnostic Categories of Infants in Program

	Up To June, 1972		From July-Sept., 1972	
	No.	%	No.	%
Down's Syndrome	16	48	1	7
Psychomotor Retardation	7	21	6	43
Cerebral Palsy	5	15	2	14
Delayed Development	2	6	2	14
Microcephaly	1	3	0	0
Hydrocephaly	1	3	1	7
Sturge Weber Syndrome	1	3	0	0
Apert's Syndrome	0	0	1	7
Blind	0	0	1	7
Totals	33		14	

TABLE 2 Ethnic Background of Infants in Program

	Up to June, 1972		From July-Sept., 1972	
	No.	%	No.	%
Hawaiian	2	6	0	0
Chinese	1	3	1	7
Japanese	12	36	4	28
Filipino	2	6	2	15
Caucasian	8	24	2	15
Multi-Racial	8	24	5	35
Totals	33		14	

TABLE 3 Sources of Referrals

	Referrals ending June, 1972 No.	%	Referrals July-Sept., 1972 No.
Private Physician	4	12	4
Crippled Children's Branch Department of Health	19	58	5
Public Health Nurse	4	12	4
Self referral	4	12	0
Waimano Training School and Hospital	0	0	1
Hawaii Association to Help Retarded Children	2	6	0
Totals	33		14

TABLE 4 Significant Correlations Related to Percentage of Program Attendance

Progress during the past year	r= .778+
Problem solving	r= .669+
Number of organizations husband belongs to	r=-.439*
Awareness and understanding of child's condition	r= .417*
Infant's ability to get along with family members	r= .405*
Referred by public health nurse	r= .590*

+correlation significant beyond the .01 level
*correlation significant beyond the .05 level

TABLE 5 Significant Correlations from Social Evaluations of 23 Families

Parental awareness and understanding of child's handicap with:	
Positive change in husband	r=.454*
Positive change in wife	r=.543+
Problem solving	r=.542+
Diagnosis of Down's syndrome	r=.564+
Amount of care needed by handicapped infant with:	
Change in family's daily living routine	r=.446*
Positive change in husband	r=-.440*
Support of relatives	r=-.441*
Diagnosis of cerebral palsy or hydrocepolus	r=.429*
Change necessitated in family activities with:	
Restriction of parent activities	r=.784+
Diagnosis of cerebral palsy or hydrocephalus	r=.470*
Diagnosis of Down's syndrome	r=-.468*
Change in educational/occupational goals of family with:	
Restriction of parent activities	r=.454*
Number of organizations husband belongs to	r=.454*
Parents use of outside activities with:	
Families consideration of institutionalization	r=.473*
Positive change in wife	r=-.421*
Increased communications	r=-.656+
Positive change in husband with:	
Positive change in wife	r=.846+
Increased communications	r=.496*
Support of relatives	r=.479*
Age of parents in the 40-50 range	r=.596+
Positive change in wife with:	
Increased communications	r=.490*
Number of organizations wife belongs to	r=.411*
Age of parents in the 40-50 range	r=.434*
Increased communications with:	
Agreement re handling the child	r=.610+
Similarity of goals of husband and wife	r=.665+
Use of outside activities	r=.656+

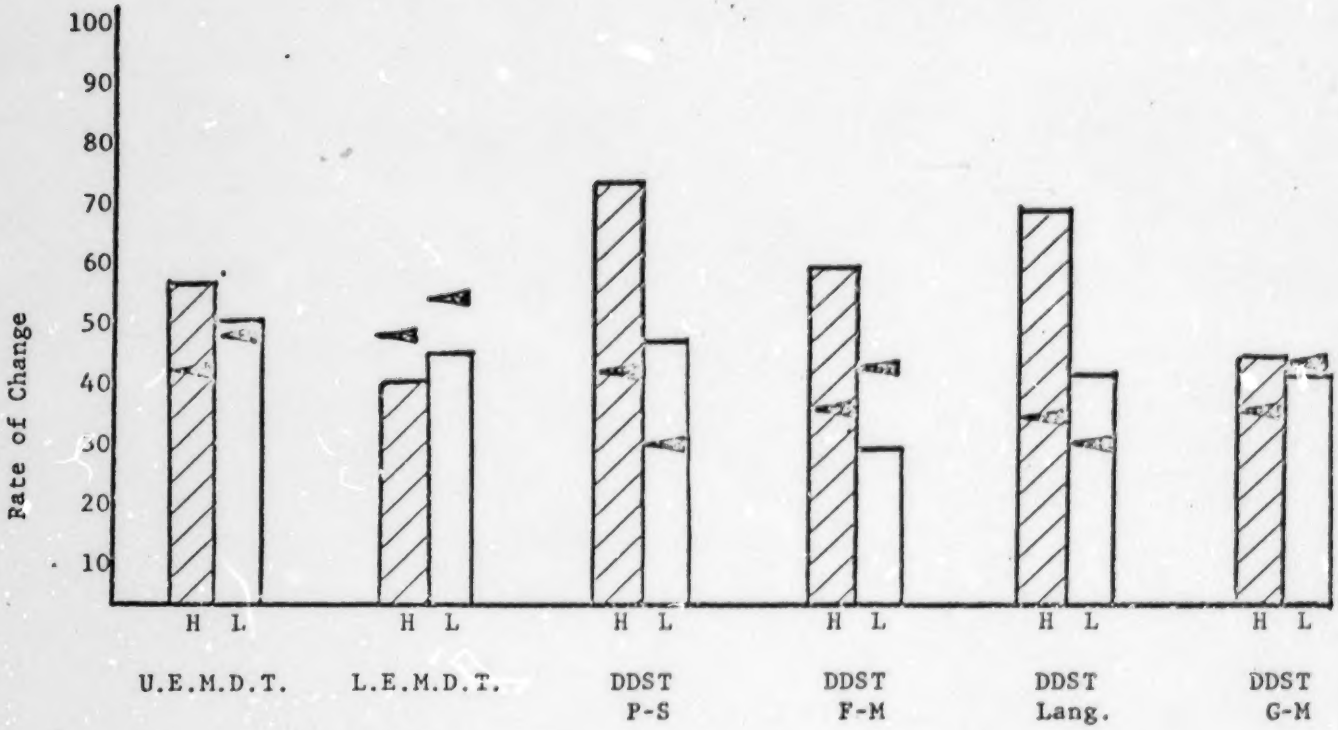
+correlation significant beyond the .01 level
*correlation significant beyond the .05 level

TABLE 6 Age Range of Infants at Referral

	Referrals ending June 1972		Referrals July-September, 1972	
	No.	%	No.	%
12 months and below	17	52	4	2
13-18 months	4	12	6	4
18-24 months	3	9	4	2
24-36 months	9	27	0	
Total	33		14	

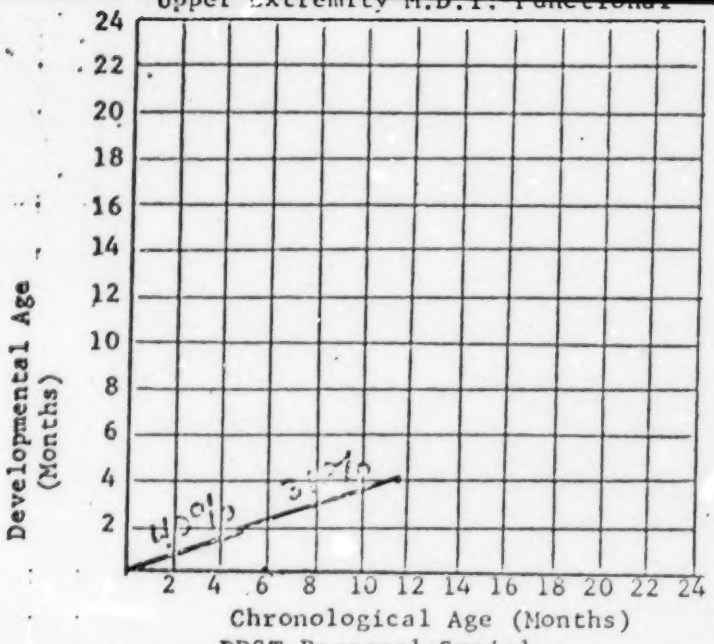
FIGURE 1

Mean Rate of Change by Infants on Six Developmental Sub-Tests Comparing High and Low Attenders and their Pre and Post Test Rates



—Post Test
Pre Test
H- High Attenders
L- Low Attenders

U.E.M.D.T. - Upper Extremity Motor Development Test
L.E.M.D.T. - Lower Extremity Motor Development Test
DDST - Denver Developmental Screening Test
P-S - Personal Social
F-M - Fine Motor Adaptive
Lang. - Language
G-M - Gross Motor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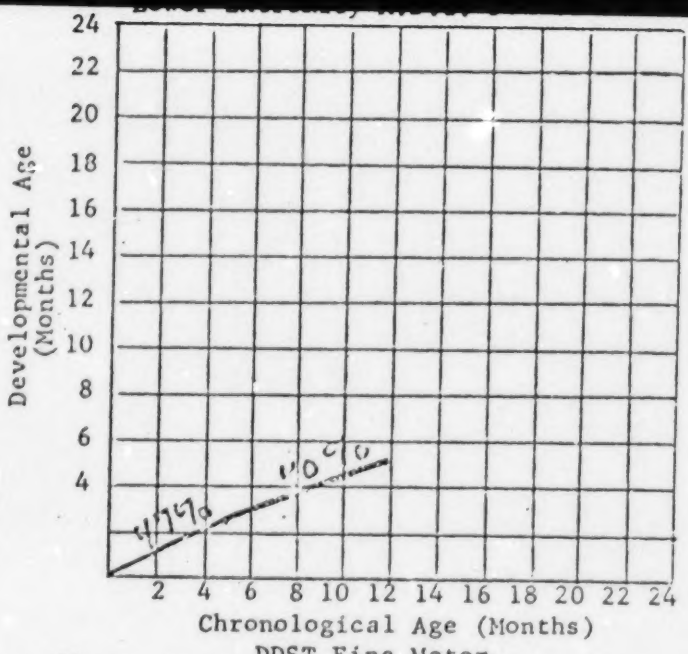
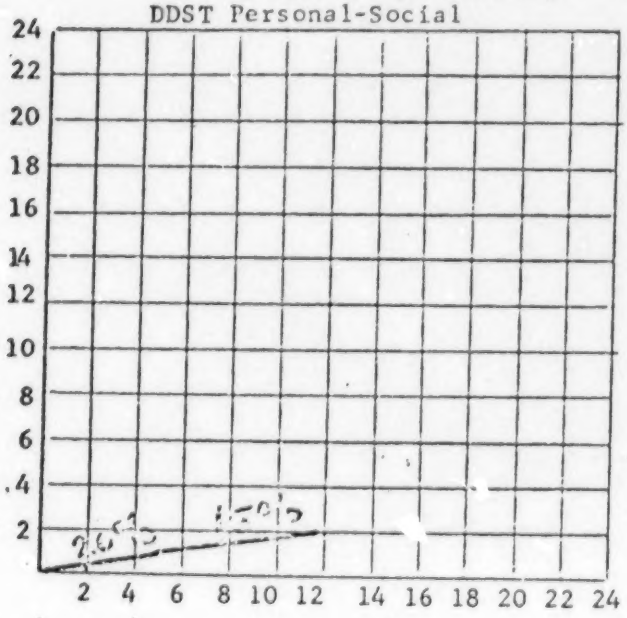
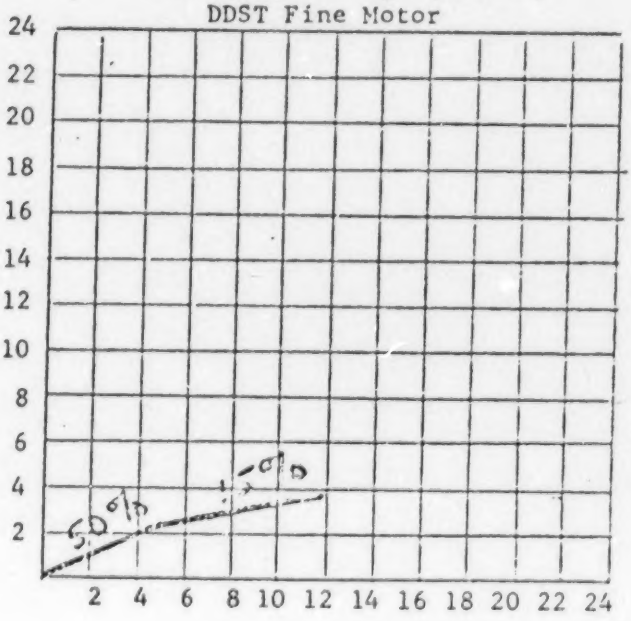
Chronological Age (Months)


Developmental Age (Months)
Chronological Age (Months)


DDST Personal-Social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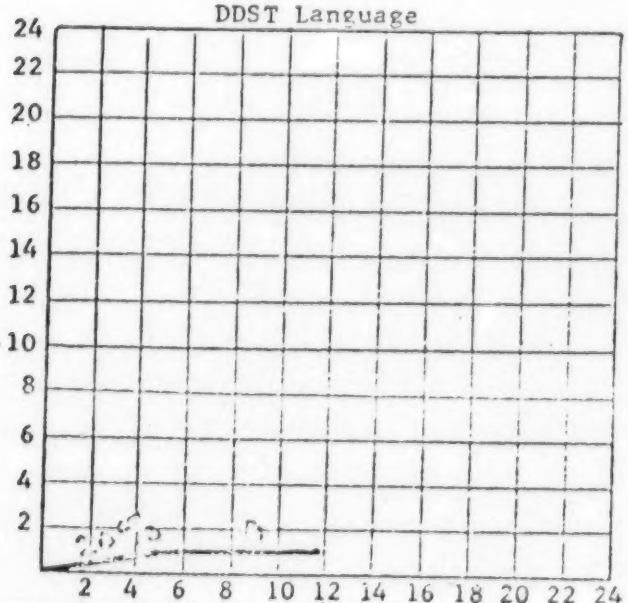
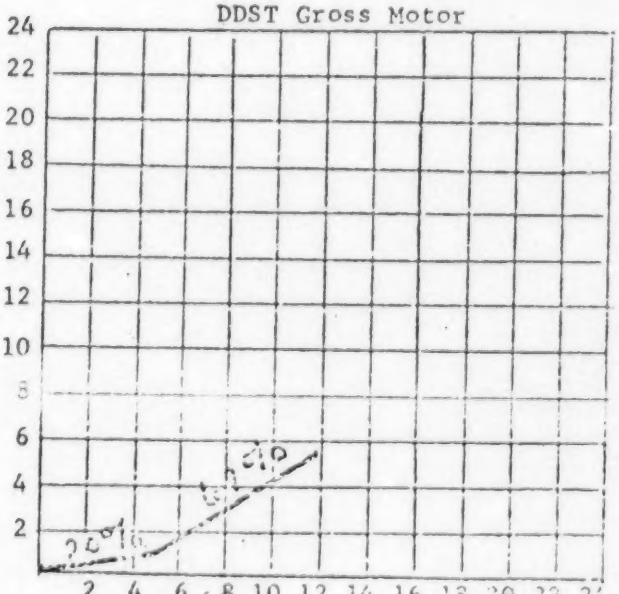
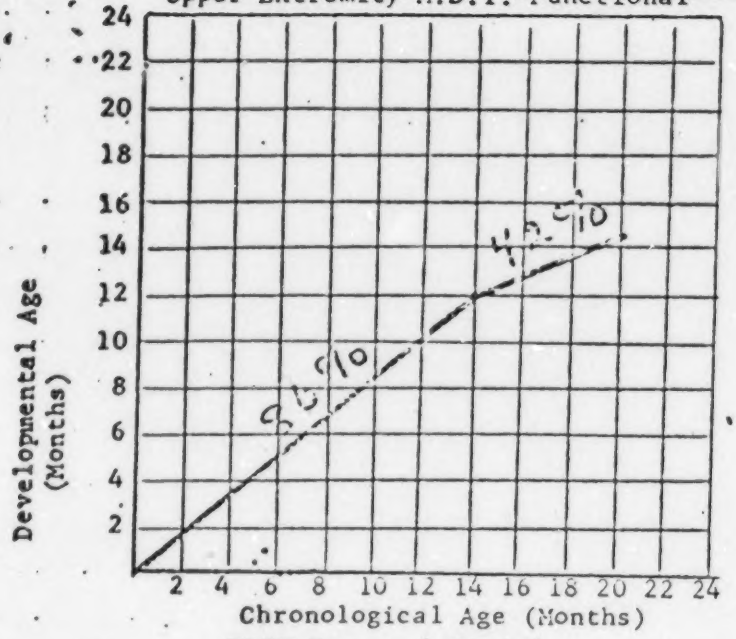
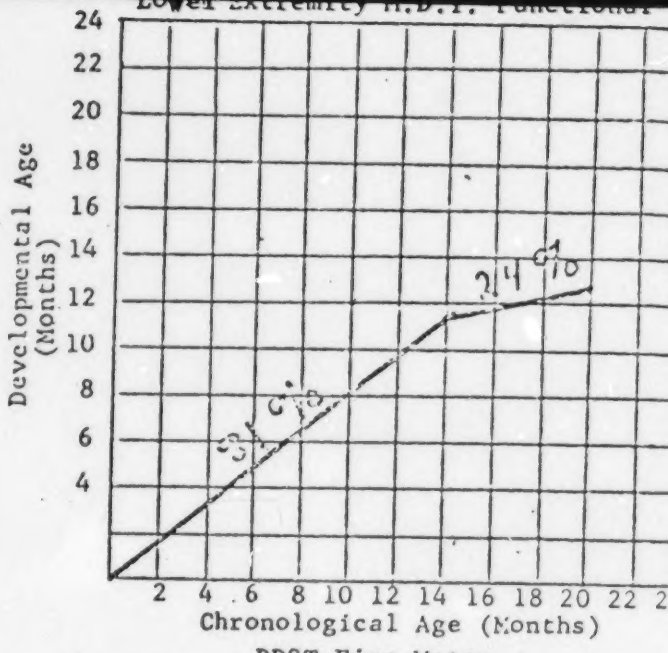

DDST Language


DDST Gross Motor

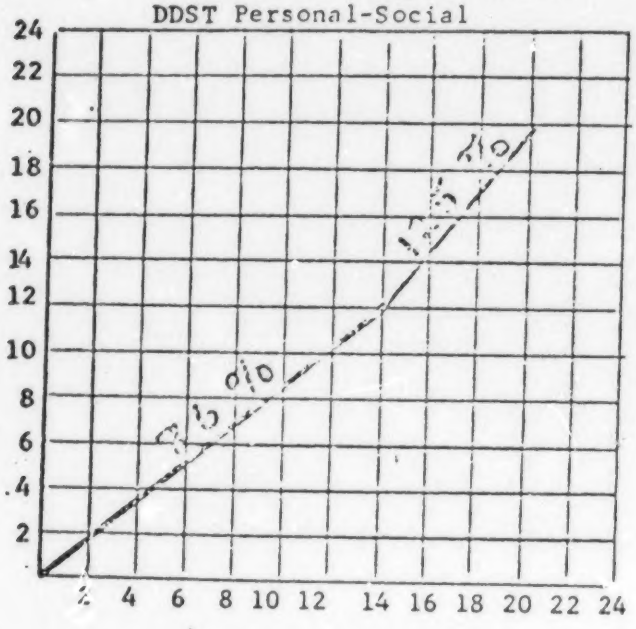
Upper Extremity N.D.I.-Functional



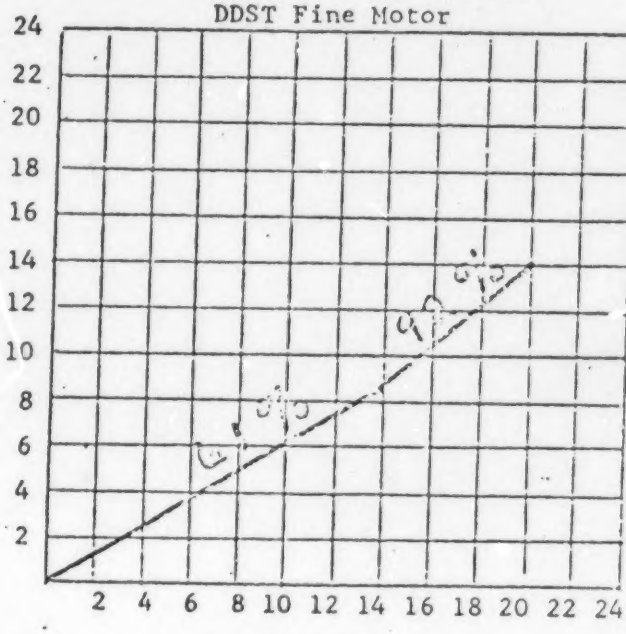
Lower Extremity N.D.I. Functional



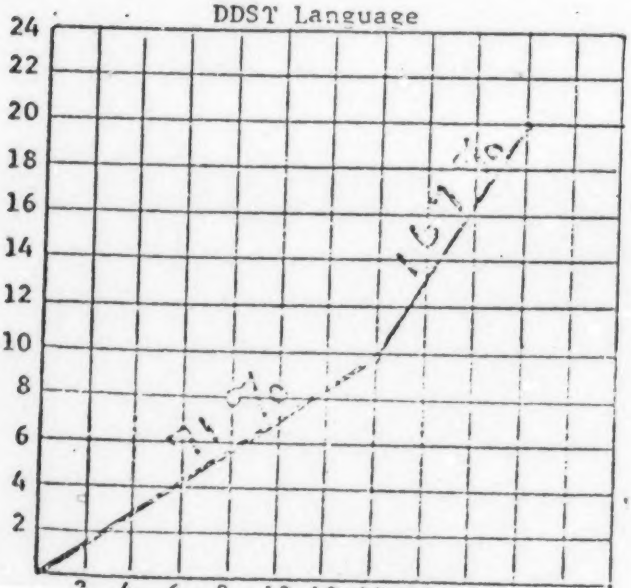
DDST Personal-Social



DDST Fine Motor



DDST Language



DDST Gross Motor